DEAFNESS FORUM AUSTRALIA

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Reclaiming the NDIS
We have to do it together.

If we're going to reclaim the NDIS, we have to do it together.

Reducing the growing cost of the National Disability Insurance Scheme has been applauded as one of biggest savings of the 2024-25 Federal Budget, with the Albanese government promising to claw back savings of $14.4bn over the next four years.

By Hayley Stone, Director of Policy and Advocacy for Deafness Forum Australia.

How do we make sure the Government's vision of 'getting the NDIS back on track' aligns with the hopes and aspirations of the community, when there's an election looming, and Labor is on a fast-track agenda to rein in the Scheme?

The Federal Budget reinforced something we've known for some time - that the Albanese Government is extremely concerned with the rising cost of the NDIS and is determined to bring its costs down.

We can only imagine Labor has a complex relationship with the Scheme – like a birth parent who saw their child raised by someone else and has been left with an adolescent NDIS they believe now has some serious boundary issues.

We know that the stakes are high for the Government. In a fragile economy, with an election as early as the end of the year, Labor needs to be seen to be tightening its belt, and the NDIS is one of their key vulnerabilities. The conservative media knows it too, and has been playing it up for years, while the Coalition has remained quiet. Too quiet.

At the same time, the NDIS has positively changed the lives of tens of thousands of people with disability across Australia, giving many access to support and services they could never have dreamed of a decade ago.

Participants in the NDIS and their families, who fought long and hard for both the Scheme and the individual day-to-day benefits they receive, will tenaciously battle to keep those supports and services. Hence, Labor finds itself accountable both to the disability community and vulnerable to the sensitivities of the broader voters.

There's no win here, except perhaps to move as quickly as possible to get the worst of it over, so the hurt is less raw when they call the election – certainly, this seems to be Labor's approach to date.

And there's another threat looming. While many are waiting for Labor's formal response to the recommendations of last year's Independent NDIS Review report to 'get the scheme back on track', it will be equally important to know the Coalition's position. There is a risk that a different Government might not maintain the

full five-year trajectory set out by the Independent NDIS Review to 'get the scheme back on track'. The best way for Labor to protect the scheme is to lay down as much groundwork as possible to safeguard its vision before the election. It makes political sense for Labor to start up the machinations and get them to a point where the Coalition is as fiscally and reputationally tied to a particular path as it can be. But even so, there are no guarantees.

We can't escape the fact that the NDIS is highly politicised and is likely to remain so for some time. Eventually, we can hope it will become, like Medicare and other social support mechanisms, simply another component of Australia's social support infrastructure, considered so basic, so fundamental, that no one would ever challenge the investment.

Up until this point, we're as much in a conundrum as Labor is. People with disability need to be heard across changes that will undoubtedly affect their lives, but it's clear there's limited time, and limited seats being offered at the consultation table.

We could push back on the Government's approach, but we may well be setting ourselves up for more pain in the long run if we do. If we slow the pace of the work we may find the foundational building of the new Scheme being left to a new, potentially less engaged Government, whatever its political alignment.

An advocacy sector representing the interests of many diverse cohorts needs to create efficiencies around how it engages with the Government on coming reforms to the NDIS and work smarter to advocate for a unified vision of an effective and equitable support system for all people with disability. We need to identify common priorities and set collective expectations for the Government around how it engages with people with disability, their families, and the Disability Representative Organisations that represent them. And we need to make sure any opportunities to participate in the reform process represent the best use of our collective time and resources. This means knowing which cohorts have the most to gain or lose on specific issues and giving the spotlight to those who need it when they need it, at a time when we are all feeling vulnerable and stretched. It also means making sure we're united on the same basic goals and that our messaging is clear and consistent.

I need to be clear that I'm not suggesting that disability representative organisations stop prioritising the interests of those they represent for some 'greater good'. They should always remain accountable to their memberships and put their interests first, but we need to break out of the silo culture we've been forced to occupy and start to look for common goals and work together to achieve them.

A key goal at this stage in the reform process should be making sure there is a legislative requirement for government to work in genuine codesign with disability representative organisations and the broader disability community across the five-year reform process. We also need to make it clear what codesign means and hold the Government firmly to account if it falls short of our expectations.

The pace of reform being pushed through, and limited opportunity for giving feedback also increases the value of network organisations: the pressure will be on these organisations to consult with their members and genuinely advocate across their collective interests.

Lastly, we need to collectively change public dialogue about the NDIS. We need to emphasise the positives of the scheme as a world first, which not only supports more than 649,000 participants, but is a critical component of the Australian service economy, creating tens of thousands of jobs and substantial economic activity, at a time when our economy lags.

If pre-federal election promises are to be made about the NDIS, we need to know that those promises will focus on building on the progress that the NDIS has already made towards supporting individuals with disability to participate equally in community, social, economic and daily life activities, and not on cuts that could take us backwards.

Deaf Indigenous Dance Group celebrates.

The Deaf Indigenous Dance Group from Far North Queensland is celebrating its 27th year with a dynamic showcase at the State Library of Queensland.

This exhibition, titled “Deaf in Dance,” features a rich array of artworks, performances, and digital stories designed with a strong focus on accessibility.

Also known as DIDG, the dance group has a unique approach, with dancers sensing the rhythms of traditional music through vibrations. To make the experience inclusive, the showcase includes monthly Auslan tours, a Braille gallery map, and audio descriptions.

Highlights of “Deaf in Dance” include over 70 narrative portraits by photojournalist Sean Davey, interviews with DIDG members, and tactile artwork by First Nations artist Breanna Buttenshaw. Visitors can also view a video of DIDG’s 2023 performance at Sydney’s Dance Rites.

Founded in Cairns in 1997 by Priscilla Seddon and Deaf First Nations Elder Patty Morris-Banjo, DIDG celebrates First Nations people who are Deaf. Morris-Banjo’s history as part of the Stolen Generation, when many Deaf children were forcibly removed from their families and culture, deeply influences the group’s mission.

For Sue Frank, the Deaf Indigenous Dance Group was the only place she felt she belonged when she was leaving school. Now president of the DIDG, she said it represents empowerment for her community.

"When I was growing up there was nothing like this, there were no opportunities, we didn't have role models, we didn't know people who could achieve what we've done, Ms Frank said.

After debuting at a dance festival in 2021 and headlining NAIDOC Week celebrations in Cairns, DIDG continues to share its story and culture.

Queensland’s Minister for the Arts, Leeanne Enoch sees it as a step in the Queensland Government’s “Creative Together” strategy to uplift First Nations culture globally and to foster truth-telling and healing.

The “Deaf in Dance” exhibition is at the State Library of Queensland until 16 March, 2025.

More Inclusive and Accessible Homes.

Deafness Forum Australia contributed to new guidelines for creating more inclusive and accessible homes.

Our feedback to the Australian Human Rights Commission's consultation highlights the importance of designing homes that meet the unique needs of people with hearing loss, and those who communicate using Auslan.

Our submission discusses how people with hearing loss or deafness experience their environment differently, often relying more on visual and tactile cues for orientation and safety. The proposed design features aim to create comfortable and functional spaces for them, such as larger open-plan living areas, wide hallways, and visual or tactile alerts for safety threats like fires.

Additionally, our submission emphasises the importance of co-design, involving people with lived experience of disability in the design process. This approach ensures that homes meet basic needs and enhance the quality of life for people with hearing loss and others with disability.

Innovative Disaster Preparedness Grant.

A West Australian Deaf Services organisation has been awarded a $650,000 grant from the National Disaster Risk Reduction Grant Program.

This funding for Expression Australia will spearhead a vital program to enhance the communication abilities of first responders with the Deaf community during disasters.

The Grant Program, which has allocated over $12.5 million to various projects across Western Australia, focuses on increasing the resilience of disaster-prone communities. This round saw 15 new projects funded to mitigate the risks and impacts of bushfires and floods. Expression Australia's project is a standout, focusing on bridging communication gaps during emergencies, which is crucial for the safety and Deaf individuals.

The Australian Census report shows slightly more than 16,000 people use Auslan. 2,000 live in Western Australia.

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The Journey from Newborn Hearing Screenings to Effective Treatment.

Imagine the joy of welcoming a newborn into the world, coupled with the immediate responsibility to ensure they have the best start in life.

This is where the Universal Newborn Hearing Screening plays a crucial role, especially in detecting Conductive Hearing Loss in infants right after birth.

Conductive Hearing Loss, commonly caused by conditions like Otitis Media—a prevalent middle ear disease during childhood—can significantly affect a child's development if not diagnosed and treated promptly. However, while screening can pinpoint potential issues, the journey that follows the initial detection is critical and, at times, complex.

The path from screening to otolaryngology—the branch of medicine dealing with ear, nose, and throat conditions—is fraught with hurdles, chiefly long wait times. Data suggests that wait times for an initial otolaryngological assessment in public facilities can stretch up to several months, with urgent referrals taking over a month and semi-urgent nearly a year. This delay is concerning, given the developmental stakes for these infants.

The referral process itself hinges on meticulous triage based on initial Universal Newborn Hearing Screening and audiology results, yet there's a striking lack of comprehensive study on how these infants are managed post-referral. While general studies indicate a high prevalence of middle ear diseases in older children, specific insights into infants' diagnosis right after Universal Newborn Hearing Screening are sparse.

A study focusing on school-aged children found low percentages of various ear pathologies, yet in contrast, the rates of middle ear issues among Indigenous children in Australia are alarmingly high, pointing to a crucial need for targeted ear health interventions from a young age.

The scenario becomes even more pressing when considering the medical interventions available. From a simple 'watch and wait' approach to prescribing antibiotics or more invasive surgical interventions like myringotomy—where fluid is drained from the middle ear—choices vary, and their outcomes deeply impact a child's ability to hear and, consequently, to learn and interact.

Consider the journey of infants identified through Universal Newborn Hearing Screening with Conductive Hearing Loss, referred for further otolaryngological assessment. Each case presents unique challenges based on a myriad of factors including the severity of the hearing loss and associated conditions, which require nuanced handling. The study conducted in partnership between the University of Queensland and Children's Health Queensland Hospital and Health Service sheds some light on these intricate paths.

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The findings reveal that many of these infants, particularly those with additional risk factors for hearing loss, often face prolonged waits for assessment and intervention. This delay not only hampers the effective management of Conductive Hearing Loss but also highlights the broader systemic issues in accessing specialised otolaryngological services.

This extensive wait for treatment underscores a critical gap between screening and care, necessitating a deeper investigation into the barriers that delay early and essential otolaryngological intervention. Further research is essential to streamline processes, reduce wait times, and improve overall outcomes for these vulnerable infants.

As we continue to advocate for improved health policies and practices, the experiences of these infants remind us of the urgency to refine our approaches to healthcare delivery. The journey from a newborn hearing screening to receiving timely and effective treatment is pivotal, not just for the health of the child but for their overall future potential. The aim is that every child detected with Conductive Hearing Loss through Universal Newborn Hearing Screening navigates a timely, clear path to the care they need.

From Science Direct.

A. Collins, R. Beswick, C. Driscoll, J. Kei, L. Traves, Otolaryngology outcomes of infants with conductive hearing loss identified through universal newborn hearing screening, *International Journal of Pediatric Otorhinolaryngology*, https://doi.org/10.1016/j.ijporl.2024.111970.

BHP has partnered with the Ear Science Institute Australia, dedicating $825,000 to its Healthy Hearing Outback program.

This significant funding will enhance ear and hearing health services for Aboriginal families in the East Pilbara region in close collaboration with the Puntukurnu Aboriginal Medical Service and other key stakeholders.

The three-year investment will create access to vital ear and hearing services directly in the country, minimising the necessity for travel. The funds will:

- Provide both onsite and portable ENT and Audiological equipment
- Employ two Martu Community Liaison Officers to ensure the integration of services within the community
- Enhance ear health promotion activities, offering culturally safe education and information
- Build the skills and knowledge of local healthcare providers, particularly Martu and Nyiyaparli clinicians
- Reduce barriers for individuals needing surgical interventions in Port Hedland and Perth.

Sandra Bellekom, CEO of Ear Science, said the Healthy Hearing Outback project promises long-term benefits for families in Newman, Jigalong, Punmu, Parnngurr, and Kunawarritji, creating a lasting impact.

Tips for Preventing Lost Hearing Aids.

Losing a hearing aid can be an anxiety-inducing event, especially when you rely on it daily for clear communication. Here are the top ten tips to keep your hearing aids safe and sound.

1. Always Use the Case or Charger

The simplest way to avoid misplacing your hearing aids is to consistently store them in their charging case. This not only keeps them safe but ensures they are charged and ready when you need them.

2. Be Careful When Undressing

Clothing can often snag hearing aids and fling them far from safety. Jo recalls a costly incident involving a camera strap and a river. To avoid similar mishaps, always double-check your hearing aids when removing items worn around your head or neck.

3. Keep Away from Pets and Children

Both curious pets and children might see hearing aids as intriguing toys. Keep them out of reach to avoid damage.

4. Ensure Proper Fit

A well-fitting hearing aid is less likely to fall out and become lost. If yours feels loose, consult your hearing care provider for a better fit. Sport locks or custom moulds can provide additional security, particularly useful for active individuals or those with uniquely shaped ears.

5. Choose Bright Colours

Opting for a brightly coloured hearing aid or earmold can make it easier to spot if it falls out.

6. Use Retention Clips

For those leading an active lifestyle or children, retention clips or devices can secure hearing aids to clothing, reducing the risk of loss.

7. Track with Technology

Technology like Apple's AirTag can be attached to hearing aid clips, helping to locate them if they go missing.

8. Label Everything in the Hospital

Use a brightly coloured container with clear labels to store your hearing aids during hospital stays. This simple measure can prevent them from being misplaced or accidentally discarded.

9. Establish Care Routines

For caregivers, establishing a routine for handling a loved one's hearing aids can prevent losses. Regularly placing the devices in marked containers can help maintain their safety and ensure they are easily found.

10. Empower Children

Teaching children to take ownership of their hearing aids and encouraging them to follow routines for their care can foster responsibility and reduce the likelihood of loss. Using name labels on their hearing aids can also help ensure they're returned if lost.

By following these guidelines, hearing aid users can significantly reduce the risk of losing these essential devices.

By Carly Sygrove for HearingTracker

Potential Drug to Combat Hearing Loss from Loud Music, Ageing.

A person's hearing can be damaged by loud noise, aging and even certain medications, with little recourse beyond a hearing aid or cochlear implant. But now, researchers have found a gene that links deafness to cell death in the inner ear in humans.

But now, University of California - San Francisco (UCSF) scientists have achieved a breakthrough in understanding what is happening in the inner ear during hearing loss, laying the groundwork for preventing deafness. Their research, published in the Journal of Clinical Investigation Insight, links animal studies on hearing loss with a rare type of inherited deafness in humans. In both cases, mutations to the TMTC4 gene trigger a molecular domino effect known as the unfolded protein response (UPR), leading to the death of hair cells in the inner ear.

Intriguingly, hearing loss from loud noise exposure or drugs such as cisplatin, a common form of chemotherapy, also stems from activation of the UPR in hair cells, suggesting that the UPR may underly several different forms of deafness.

There are several drugs that block the UPR – and stop hearing loss – in laboratory animals. The new findings make a stronger case for testing these drugs in people who are at risk of losing their hearing, according to the researchers.

"Millions of American adults lose their hearing due to noise exposure or aging each year, but it's been a mystery what was going wrong.

"We now have solid evidence that TMTC4 is a human deafness gene and that the UPR is a genuine target for preventing deafness," said Dylan Chan, MD, PhD, co-senior author on the paper and director of the Children's Communication Center in the UCSF Department of Otolaryngology.

How hair cells in the ear self-destruct

In 2014, Elliott Sherr, director of the UCSF Brain Development Research Program and co-senior author of the paper, noticed that several of his young patients with brain malformations all had

mutations to TMTC4. But laboratory studies of this gene soon presented a conundrum.

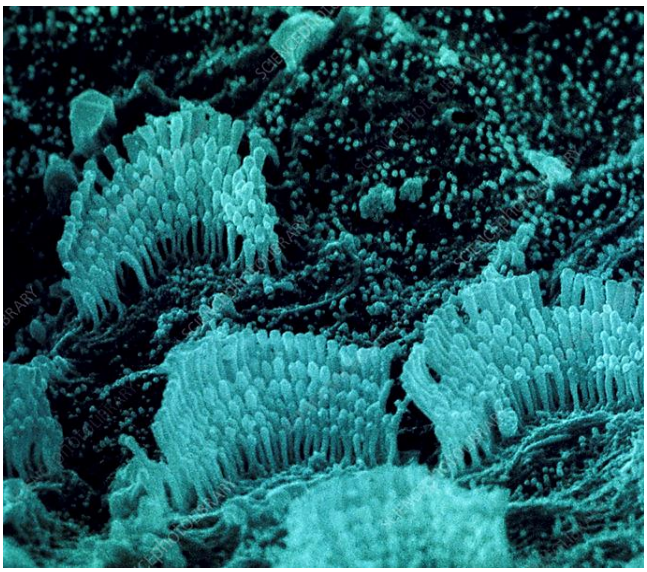
"We expected mice with TMTC4 mutations to have severe brain defects early on, like those paediatric patients, yet to our surprise, they seemed normal at first," Sherr said.

"But as those animals grew, we saw that they had gone deaf after they had matured."

Sherr partnered with Chan, an expert on the inner ear, to look into what was happening to the mice, which looked like an accelerated version of age-related hearing loss in humans.

They showed that mutations to TMTC4 primed hair cells in the ear to self-destruct, and loud noise did the same thing. In both cases, hair cells were flooded with excess calcium, throwing off the balance of other cellular signals, including the UPR.

But they found there was a way to stop this. ISRIB, a drug developed at UCSF to block the UPR's self-destruct mechanism in traumatic brain injury, prevented animals who were exposed to noise from going deaf.



The first adult human deafness gene

In 2020, scientists from South Korea, led by Bong Jik Kim, connected Chan and Sherr's 2018 findings with genetic mutations they found in two siblings who were losing their hearing in their mid-20s.

"It's rare to so quickly connect mouse studies with humans," Sherr said.

"Thanks to our Korean collaborators, we could more easily prove the relevance of our work for the many people who go deaf over time."

Kim, an otolaryngologist at the Chungnam National University College of Medicine (Korea), facilitated the shipping of cells from those patients to UCSF. Sherr and Chan tested those cells for UPR activity and found that, indeed, this flavour of TMTC4 mutation turned on the destructive UPR pathway in a human context.

When Chan and Sherr mutated TMTC4 only in hair cells in mice, the mice went deaf. When they mutated TMTC4 in cells from individuals in the Korean family who hadn't gone deaf, and in laboratory human cell lines, the UPR drove the cells to self-destruct. TMTC4 was more than a deafness gene in mice – it was a deafness gene in humans, too.

Translating a discovery to prevent deafness

Understanding TMTC4 mutations gives researchers a new way of studying progressive deafness, since it is critical for maintaining the health of the adult inner ear. The mutations mimic damage from noise, ageing or drugs like cisplatin.

The researchers envision a future where people who must take cisplatin, or who have to be exposed to loud noises for their jobs, take a drug that dampens the UPR and keeps hair cells from withering away, preserving their hearing.

The science also suggests that the UPR could be targeted in other contexts where nerve cells become overwhelmed and die, including diseases long thought to be incurable, like Alzheimer's or Lou Gehrig's disease.

"If there's any way that we can get in the way of the hair cells dying, that's how we're going to be able to prevent hearing loss," Chan said.

Learn more at https://ucsf.edu, see the Fact Sheet, or read the full story by Mirage.

Hearing Restored in Pioneering Gene Therapy Trials.

BRITAIN: Opal's mum says she was "gobsmacked" when she realised her daughter could hear without her cochlear implant - and experts say the results are better than they expected.

18-month-old Opal Sandy had her hearing restored, becoming the first person worldwide to take part in a new gene therapy trial.

Opal was born totally deaf due to auditory neuropathy, which disrupts nerve impulses from the inner ear to the brain.

Opal was treated at Addenbrooke's Hospital in Cambridge. The head of the trial, Professor Manohar Bance, said results were "better than I hoped or expected" and he hopes medics might be able to cure others with this type of deafness.

Consultant paediatrician, Professor Richard Brown said, "We have results from Opal which are very spectacular - so close to normal hearing restoration. So we do hope it could be a potential cure," he said.

Opal had an infusion of the working gene into her right ear during surgery. Her parents noticed changes in only four weeks and the improvements were especially noticeable 24 weeks later. Jo and James Sandy said they were "gobsmacked" when she responded to sound tests at home without her cochlear implant, the usual way to treat the condition.

"I thought it was a fluke or like a change in light or something that had caught her eye, but I repeated it a few times," said Mrs Sandy.

They say she now enjoys the sound of slamming her cutlery on the table and playing with toy drums and wooden blocks.

Opal's surgery was very similar to fitting a cochlear implant, according to Prof Bance. He said the inner ear (cochlea) was opened and the treatment infused using a catheter over 16 minutes.

"We have to make a release hole in another part of the ear to let the treatment out because it has to go all the way through the ear," he said.

"And then we just repair and close up, so it's actually a very similar approach to a cochlear implant, except we don't put the implant in."

He said the gene therapy potentially "marks a new era in the treatment for deafness".

"It was just the fact that we've been hearing about this for so long, and there's been so much work, decades of work... to finally see something that actually worked in humans... It was quite spectacular and a bit awe-inspiring really," he said.

The treatment was developed especially for children with OTOF mutations, and a second child who has had the same surgery is also seeing positive results.

The trial has three parts - with three deaf children, including Opal, getting a low dose in just one ear. Another three children will get a high dose on one side. Then, if safe, a new set of children will get a dose in both ears at the same time.

Revolutionary AI Headphones Enhance Listening in Crowded Spaces.

Researchers at the University of Washington have pioneered an artificial intelligence system known as "Target Speech Hearing," which promises to redefine auditory experiences in noisy environments.

Unlike traditional noise-cancelling headphones that block out all sound, this innovative system allows users to single out and listen clearly to one person's voice in a crowd.

The technology uses AI-equipped headphones to "enrol" a speaker when the user looks at them for a few seconds. The system captures the speaker's voice patterns through microphones embedded in the headphones, isolates that voice, and delivers it directly to the user's ears. This makes it possible to hear that person even in a noisy place or if the user moves around.

The device significantly improves how we interact with sound. The initial setup requires the listener to face the speaker to capture their voice effectively, with a permissible alignment error of 16 degrees.

This technology, while still in the proof-of-concept stage and not yet available commercially, holds immense potential. It could revolutionise everyday communication in public spaces, where ambient noise often compromises clarity. Moreover, it could be a game-changer for individuals with hearing impairments, offering them a new level of auditory clarity. The system recognises a speaker's unique vocal patterns and continually focuses on their voice as it receives more data, enhancing clarity over time.

The development team is also exploring potential expansions of this technology into earbuds and hearing aids.

While the system currently can only enrol one speaker at a time and may struggle with voices from the same direction, the development team is actively working on improvements. If a user finds the sound quality less than satisfactory, they can run another enrolment process to enhance clarity. This commitment to continuous enhancement instils optimism about the technology's future potential.

This project represents a step forward in using AI to manipulate auditory perception, tailoring it to user preferences in real time. It builds on the team's previous work on "semantic hearing," which allowed users to choose specific types of sounds to hear, like voices or birds, while cancelling other background noises.

The implications for future personal audio devices are profound, promising more personalised and accessible listening experiences.

For more information, email the team at tsh@cs.washington.edu

Lung Foundation Australia is seeking Expressions of Interest for the Lung Cancer Screening Consumer Committee.

The committee will provide advice and feedback on resources and communication materials that will support the roll out of the National Lung Cancer Screening Program.

By joining, you can provide your unique insights and experiences to help create a diverse committee that will champion an equitable and inclusive screening program.

Lung Foundation Australia welcomes participation from members of the community who have experience, both positive and negative, in accessing healthcare. This can include people living in rural and remote communities, people living with disability, people living with mental health conditions, people from non-English speaking backgrounds, and people in the LGBTQIA+ community.

At the moment, tobacco or former tobacco use is one of the key eligibility criteria for lung cancer screening. If you have a history of tobacco use, you are also welcome to express your interest in joining, to help educate and support the committee's activities in reducing stigma around smoking.

Lung Foundation Australia has long championed fairness and rest assured this committee will be a positive, non-judgmental, and safe environment for you.

For more information visit Lung Foundation Australia's website or email abbyf@lungfoundation.com.au

To express your interest in being involved, click here.

Know someone who deserves their own copy of One in Six?

Let us know via hello@deafnessforum.org.au